

Current Issues in Developmental Disabilities

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DEVELOPMENTALLY DISABLED PERSONS increasingly are moving out of institutions and into the community. For practicing physicians, working with this population can require anything from getting through the maze of federal and state definitions and eligibility requirements to taking the extra minutes to put a frightened patient at ease. Providing conscientious care can require an understanding of legal, psychological and social as well as medical issues. In this article we seek to acquaint physicians with some of the issues in caring for developmentally disabled patients: legal definitions, service systems, philosophy of treatment, barriers to care and obtaining consent.

Identifying the Developmentally Disabled

In 1970 landmark federal legislation called the Developmental Disabilities Assistance and Bill of Rights Act (PL 91-517) called for a nationwide system to address the needs of persons with developmental disabilities that would include state planning councils for developmental disabilities, systems for protection and advocacy of the rights of persons with developmental disabilities and grants to university-affiliated facilities for training, research and service demonstration programs.

In institutionalizing the term "developmental disabilities," this legislation instigated a gradual move from a categorical diagnosis of the disabling condition—such as "mental retardation"—to a functional definition based on a person's limitations and need for services.

The Developmental Disabilities Assistance and Bill of Rights Act has been amended several times since its passage in 1970, including amendments in 1984 in PL 98-527. The current federal legislation defines developmental disability as:

- ... a severe, chronic disability of a person which—
- (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (B) is manifested before the person attains age twenty-two;
- (C) is likely to continue indefinitely;
- (D) results in substantial functional limitations in three or more of the fol-

lowing areas of major life activity: (i) self-care; (ii) receptive and expressive language; (iii) learning; (iv) mobility; (v) self-direction; (vi) capacity for independent living; and (vii) economic self-sufficiency; and (E) reflects the person's need for a combination and sequence of special interdisciplinary or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.¹

Any state that uses federal developmental disability money must use this definition.

A number of states use a stricter definition of eligibility for additional services funded with state dollars. Under California law, for example, developmental disabilities as defined for state services include mental retardation, cerebral palsy, epilepsy, autism or other conditions similar to mental retardation that require treatment similar to that required by mentally retarded persons. The disability must originate before age 18 years, must be likely to continue indefinitely and must constitute a substantial handicap for the person.

If asked to define developmental disability, the average practicing physician would most likely include many other disabling conditions. Not surprisingly, there is often confusion as to who is developmentally disabled, and practitioners may face frustration when a narrow definition excludes their disabled patients from state-supported services. Referring physicians must be familiar with the definition of developmental disabilities used in their state to know which disabling conditions entitle their patients to services.

Most studies of developmental disabilities have concluded that mental retardation alone occurs in about 3% of the American population—more than 6 million persons.² This figure is highly controversial because of the difficulties in defining mental retardation, but it does provide some idea of the number of Americans who may be classified as developmentally disabled.

Most people with developmental disabilities are now served in the community, reversing the trend to provide services in large-scale institutions. In the 1970s there was a 20% reduction in the number of developmentally disabled residents in public institutions.³ Deinstitutionalization is partly the result of court decisions mandating that people with developmental disabilities be treated in the least restrictive setting appropriate and partly the result of a changing consciousness among the public, policymakers, physicians and other service providers that developmental disabilities need not keep a person from participating in the mainstream of society.

The Developmental Disabilities Act of 1970, together with legislation in individual states, created a service system that now ranges from community group homes, semi-independent and independent living situations and adult day care to state hospitals and private institutions. Many children and adults with developmental disabilities are now likely to live at home, attend public schools and receive medical and other services in their own communities. As more people with developmental disabilities live and work in the community, more community physicians will be called upon to identify and treat these patients in the course of their regular practice.

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Serving Persons With Developmental Disabilities

Regional Center Systems

Individual states have chosen to use the funding provided under the 1970 federal act in different fashions, often with the addition of state monies. Most states have created systems of regional centers to identify, diagnose and provide for the treatment of developmental disabilities. For example, in Idaho, regional adult and child developmental centers provide screening, diagnosis and treatment. California has a comprehensive system of 21 regional centers operated by private, nonprofit corporations under contract with and funded by the state. Each is governed by a board of directors that contracts with the state to provide specific services. The contract is renegotiated each year. All regional centers must carry out certain activities, such as evaluation, reporting and monitoring, but each center may set policies that enable it to best serve the needs of its particular population. A regional center serving a high-density low-income population may operate quite differently from a regional center serving a low-density population. For example, Los Angeles County alone has seven regional centers, whereas one regional center serves the counties of Riverside, San Bernardino, Inyo and Mono, an area greater in size than New England. The interdisciplinary regional center staff may include physicians, nurses, nutritionists, occupational therapists, physical therapists, psychologists, social workers, genetic counselors and educational specialists.

Persons thought to have a developmental disability are referred to the regional center for diagnosis or evaluation. After eligibility has been established, the case of the "client," a term used by most regional centers, is reviewed by an interdisciplinary team (with parental input encouraged) to identify his or her living requirements, training, vocational needs and so on. Because the need for services varies greatly by intellectual level and severity of physical or mental impairment, regional center staff develop an Individual Program Plan for each client to help ensure that necessary services are provided for the person and family. The staff might also make referrals to community agencies, physicians or other support services. In addition to serving persons with developmental disabilities, regional centers also offer preventive services to persons at risk of parenting a child with developmental disabilities and to infants at risk of such disabilities developing.

Regional centers may contract with private vendors—including physicians—for the provision of necessary services under a fee structure established by the state. About 75% of developmentally disabled people served by California regional centers receive services through Medicaid (Medi-Cal). Although state eligibility rules require the onset of the disability before age 18, persons with developmental disabilities may receive services throughout their lifetime.

State hospitals are also an integral part of California's continuum of care for those with developmental disabilities. Regional centers are responsible for admissions to and discharges from the hospital and contribute to planning, evaluation and counseling for state hospital residents. Regional centers work with the hospitals to arrange for community placement and other services following discharge.

In the 19 years since the founding of the first regional center, community physicians in California have become increasingly aware of the regional centers as a resource for their

developmentally disabled patients. Primary care physicians play an important role in making families aware of regional center services and in ensuring that patients obtain the care they need.

Normalization—An Approach to Treatment

Today's approach to treating developmental disabilities is *normalization*. Simply stated, all developmentally disabled people—regardless of the degree of their impairment—have potential for growth, learning and development. All have the right to live a life to the fullest of their own abilities, and a practitioner's role is to assist them in achieving the patterns and conditions of everyday life.⁴ This philosophy encourages developmentally disabled persons—whether they are mildly or severely disabled, whether they live at home or independently, in group homes or in institutions—to develop to the fullest extent possible.

In the medical setting, normalization means that persons with developmental disabilities are accorded the same respect and rights as other patients, physical access is facilitated by ramps and suitable doors and patients are encouraged to participate in registration and history-taking to the extent their abilities allow. Physicians especially can contribute to the development of their disabled patients by encouraging them to participate in their treatment, by extending to them the same willingness to broach sensitive medical topics they display toward other patients (discussing sexual concerns, for example), by explaining the diagnosis and treatment plan in terms compatible with a patient's level of understanding and by familiarizing themselves with and making appropriate referrals to services for the developmentally disabled.

Barriers to Medical Care for Developmentally Disabled Persons

There are many barriers to providing good medical care to developmentally disabled persons—some obvious, some subtle.

From a physician's point of view, a major obstacle in treating a developmentally disabled patient is difficulty in obtaining an adequate medical history. Inability of a patient to communicate his or her symptoms or past medical history, lack of information on the part of the care provider and previous scattered and fragmented medical care can confound the most able history-taker. Another obstacle may be a patient's resistance to physical examination. Imagine a physician in the middle of a busy afternoon confronted with a person with apparent abdominal pain who cannot give a dietary or bathroom history and who is reluctant to lie down on the examining table! This situation requires great patience and skill. It also requires time. In general, developmentally disabled patients require more time in a physician's office than nondisabled patients.

Developmentally disabled patients often have exaggerated fears about visiting a physician. This problem can be ameliorated with understanding and cooperation between physicians and care providers. Some developmentally disabled patients and their care providers may feel prejudiced against the medical system, often as a result of previous negative experiences. They may feel that the medical care system does not value disabled persons and is not responsive to their needs.

Structural barriers such as buildings without wheelchair access and transportation difficulties may interfere with or

prevent patient access to medical care. In addition, language and cultural differences may impair communication and lack of financial resources may impede the provision of good medical care.

Other barriers that limit care and present special problems include

- Uncaring or lazy care providers (fortunately rare) who do not take their charge to a doctor, except in crises.
- Difficulties in communicating information among the various professionals who have a need to know what is currently being done for a patient.
- Interagency squabbles about accepting responsibility for care of the developmentally disabled, with each group waiting for the other to "pick up the check."
- Inadequate follow-up of medical problems; for instance, a tertiary care facility may discharge a patient without adequately arranging the changeover to care by a local physician.
- Problems in obtaining informed consent for treatment.
- Inadequate community services to which developmentally disabled patients may be referred for employment, social and other important services.

Physicians should examine their own attitudes regarding patients who are disabled. Past social policy to institutionalize the developmentally disabled and a lack of information in medical school can leave physicians unfamiliar with the causes and nature of these disabilities. Physicians need to make themselves aware of the definition of developmental disabilities, the needs of these patients and the community resources that will contribute to the provision of quality care.

Consent for Treatment

The average physician will at one time or another face complicated decisions of informed consent. This is especially the case for physicians who treat patients with developmental disabilities, including mental retardation. Issues of informed consent for children with developmental disabilities may be handled by means of parental consent. A mentally retarded adult presents more complex issues of informed consent because a determination of competency is required.

The capacity to give medical consent may be defined as the ability to engage in a rational process of decision making—the ability to evaluate information and to act on the evaluation. The person giving consent must be able to understand the risks, benefits and consequences of all procedures being considered. Because medical consent is always required, physicians must be prepared to judge the competency of a mentally retarded patient and to obtain consent.

There are two major means of obtaining consent: personal consent and conservatorship. The first instance concerns an adult who is considered competent. Under current law a retarded person 18 years of age or older is entitled to manage his or her own affairs unless a court decides that the person is unable to do so. A person's legal competency is not dependent on the severity of his or her disability, residency in an institution for the mentally retarded or status as a client of a service system such as a regional center. Only the court may declare a person incompetent. Thus, anyone older than 18 years who has not had a conservator or guardian appointed by a court is legally considered capable of giving informed consent. The fact that someone is retarded is not *prima facie* evidence that that person lacks this capability.

In the case of a mentally retarded person who is legally considered competent, a treating physician may need to spend extra time explaining the procedure requiring consent and to bring in family members or friends to assist in the decision making. For example, a patient asked to give consent for treatment of hereditary spherocytosis may not understand what a splenectomy is, but can understand an explanation that this organ felt or outlined by the physician is causing a serious problem and if it is removed there is a good chance that the problem will be better. The person may not understand that this operation may be immunocompromising but can understand that the organ helps fight germs and, if it is removed, then his or her ability to fight germs will not be as strong, and, further, that the germs sometimes (but not usually) can become so strong that a person could die. The patient may not be able to decide whether or not to have the operation but can understand that most people faced with this decision choose to have the operation. Finally, the patient may be willing to use the counsel of someone he or she trusts to help make the final decision.

Obviously, in many instances mentally retarded patients are not considered competent and must have a conservator appointed. A conservator who has been given specific authority to grant medical consent by a court can act for the conservatee and can sign consent forms for medical procedures.

California law allows the director of a regional center to give consent to medical, dental and surgical treatment of a regional center client in certain circumstances. If a developmentally disabled person has no legally authorized conservator, the director may consent to treatment for the client and may then initiate proceedings for the appointment of a conservator.

Most medical, surgical and dental care is available to persons with developmental disabilities through personal consent or conservatorship. Women with developmental disabilities who are capable of giving informed consent may obtain abortions and be sterilized in accordance with federal law and their own state's case law. The legality of consent by a conservator for these procedures has yet to be settled in many states, however. In California a conservator's legal right to consent to a sterilization procedure has recently been clarified.

Past decisions in California have held that there is no legal basis on which to sterilize developmentally disabled persons by means of conservatorship proceedings. For example, in the *Guardianship of Tully* case, the father of a profoundly retarded adolescent daughter brought suit to order she be sterilized. Medical and social justifications were established and were virtually undisputed. Nevertheless, the trial court and the appellate court held that they could not order an involuntary sterilization because it was prohibited by law.⁵

In October 1985, the California Supreme Court reversed these earlier decisions in the case of *Conservatorship of Valerie N.*⁶ The court found it unconstitutional to have an outright ban on sterilization of mentally retarded persons when this form of birth control is available to those deemed competent to give personal consent. While the court denied sterilization in the *Valerie N* case, this landmark decision upheld the right of conservators and their charges to obtain sterilization with court permission.

INFORMATION

In situations wherein a physician is uncertain how consent may be obtained, he or she may want to contact regional centers or similar service providers or call their state or county medical society. Other sources of information include state councils on developmental disabilities and state protection and advocacy services for persons with developmental disabilities.

REFERENCES

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4. Nirje B: Normalization principle and its management implications, *In* Kugel R, Wolfensberger W (Eds): *Changing Patterns in Residential Services for the Mentally Retarded*. US Government Printing Office, 1976, pp 179-195
5. *Guardianship of Tully*, 83 Cal App3d 698 (1978)
6. *Conservatorship of Valerie N*, 40 C3d 143 (1985)

Medical Practice Question

EDITOR'S NOTE: *From time to time medical practice questions from organizations with a legitimate interest in the information are referred to the Scientific Board by the Quality Care Review Commission of the California Medical Association. The opinions offered are based on training, experience and literature reviewed by specialists. These opinions are, however, informational only and should not be interpreted as directives, instructions or policy statements.*

Cochlear Implants for Deafness

QUESTION:

Is the use of a cochlear implant for deafness an accepted medical practice or is it experimental?

OPINION:

In the opinion of the Scientific Advisory Panel on Otolaryngology/Head and Neck Surgery, the cochlear implant procedure is considered scientifically valid when carried out by qualified physicians.